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Social Networks of Women Caregivers of Cognitively Impaired Older Persons

by

Heather Elizabeth Rycroft Fudge

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A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Nursing

Department of Nursing

Edmonton, Alberta

Spring 1995

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **Social Networks of Women Caregivers of Cognitively Impaired Older Persons** submitted by **Heather E.R. Fudge** in partial fulfilment of the requirements for the degree of **Master of Nursing**.

Anne Neufeld

Dr. Anne Neufeld, Supervisor

M J Harrison

Dr. Margaret Harrison

Dr. Herb Northcott

Date: Apr 13, 1995

DEDICATION

To my parents, **Brigid and David Crump**, who have been unfailing sources of support for all of my academic and career endeavours. They taught me the importance of caring.

To my husband **Dan**, who provided me with his love, patience and encouragement throughout my Master of Nursing education and the completion of this thesis.

Abstract

Previous research on social networks has addressed issues such as network size, yet limited attention has been given to caregivers' perceptions of the characteristics of their networks. This was a descriptive study of women caregivers' perceptions of their social networks and the support received. The study involved secondary analysis of interview data and results of the Arizona Social Support Interview Schedule of twenty caregivers, obtained in an earlier study. The data was analyzed using a code-recode process and a typology of networks was developed from the data.

Those caregivers with diverse networks, composed of a large and varied membership, were generally satisfied with the support that they received. Caregivers with kin-dominated networks, composed mainly of family, were not satisfied with the support that they received and experienced considerable conflict. This information may prove useful to practitioners in a variety of health care settings and in the design of programs aimed to promote support while caregiving.

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Chapter 1

Introduction

Social networks and the support that they provide have long been recognized as an important resource for those who are caregivers to elderly persons. Canadians are living longer and life expectancy continues to increase. For example, in 1971 the life expectancy at birth was 73 years for males and 80 years for females. By the year 2011 the life expectancy at birth is expected to be 77.2 years for males and 84.0 years for females (Statistics Canada, 1990). Presently, those persons 65 years of age or older comprise about 11 percent of the total population and that number is expected to increase to 21.8 percent by the year 2031 (Canadian Study of Health and Aging Workgroup, 1992). The rate of increase in the elderly population has outpaced the rate of increase of other age groups. For example, between 1986 and 1991 the proportion of the population aged 65 years or older increased from 10 to 12 percent while the proportion aged less than 15 years actually decreased during that time period (Statistics Canada, 1992).

The increase in longevity has resulted in an increasing number of people living with chronic diseases. Many of these individuals require assistance from professionals or family and friends, in order to live day to day. Only a small percentage of these older persons requiring assistance live in

nursing homes or other long-term care institutions, while the majority are cared for at home by spouses or other adult relatives (Staight & Harvey, 1990). These statistics demonstrate that there is an increasing number of caregivers of older persons who themselves will need support of a formal or informal nature in order to fulfil their caregiving responsibilities.

One group of older persons who require considerable assistance is those who have some degree of cognitive impairment. The prevalence of dementia is estimated at about 10 percent among those 65 years of age and older and increases to 40 percent among the very elderly (Canadian Consensus Conference on the Assessment of Dementia, 1991). The Ontario Advisory Council of Senior Citizens (1986) reports that approximately 170,000 persons in Canada have irreversible dementia (cognitive impairment) and that there are about 25,000 new cases of dementia every year (Canadian Consensus Conference on the Assessment of Dementia).

In the current context of health care reform individuals are encouraged to stay in the community for as long as possible, and to delay institutionalization until it is absolutely necessary. This has resulted in spouses and family members assuming significant responsibility for caring for these cognitively impaired older persons at home.

In a Canadian study of five different employment sectors (Canadian

Aging Research Network, 1993), 46 percent of the employees surveyed stated that they provided assistance for an older relative. In an Alberta study, McKinnon (1992) reported that 30 percent of the respondents were providing assistance to an elderly relative.

Extensive research has been done on the impact that caring for a cognitively impaired older person has on the caregiver (eg, Brodaty & Hadzi-Pavlovic, 1990; George & Gwyther, 1986; O'Neill & Ross, 1991). The results of these studies show that these caregivers experience many financial, physical, and emotional demands, and require a satisfactory and effective social support system. Many aspects of caregivers' lives, such as social activities, relationships with friends and family, time for self, and emotions experienced, are affected by their caregiving. These factors have a major impact on the physical, emotional and psychological health of the caregivers (Caserta, Lund, Wright & Redburn, 1987; George & Gwyther, 1986; Given, King, Collins & Given, 1988).

Women, particulary wives and daughters, are the predominant caregivers in our society (Brody, 1981). Lewis and Meredith (1988) report the findings of a British national survey which shows that 13 per cent of all women had caring responsibilities for sick and elderly dependents. This figure rose to 40 per cent for those women aged 40 years or more. Other studies have determined that the

majority of caregivers are indeed female (eg., Baillie, Norbeck & Barnes, 1988; George & Gwyther, 1986; Given, Stommel, Collins, King, & Given, 1990; and Wood, 1991). Many of these caregivers are confronted with the issues and concerns related to the natural aging process themselves, or have other family responsibilities and employment obligations, as well as the considerable commitment of caregiving for their cognitively impaired older relative.

As a member of the health care system, the nursing profession has long recognized the necessity to address the needs of informal (family) caregivers in our society. Public health nurses have traditionally supplied family-focused, community-based home-visiting services. They provide health-promotion and disease prevention to individuals, families and groups across the life span (Matuk & Horsburgh, 1989).

Many nurses, especially those who work in community health or in long-term care facilities, are able to assess the impact that social networks and their support have on the caregivers of cognitively impaired older persons. They recognize the need to understand the components of these support networks, in order to develop services and programs that meet these caregivers' needs.

Social networks and the support received from these networks have long been acknowledged as important correlates of an individual's well-being (Kahn

& Antonucci, 1980; Sandler & Barrera, 1984). Social networks are one of many psychosocial elements that are related to physical and psychological well-being. Israel (1982) notes that networks are comprised of structural (eg., size, density), interactional (eg., frequency, homogeneity, dispersion), and functional (eg., instrumental, cognitive, affective) characteristics and these characteristics may be associated with health in a variety of ways.

We need to more fully understand the components of caregivers' social networks in order to develop programs or strategies that enhance the caregivers' social support. These network components include the composition of social networks, the caregivers' perceptions of potential sources of support, and their satisfaction with the support received.

Women caregivers were the focus of this study because of their predominance as caregivers to this population of older persons. In addition, studies have shown that there is a difference between men and women in the experiences of caregiving (Cronewett, 1985; Fitting, Rabins, Lucas, & Eastham, 1986) and therefore it is suggested that male caregivers should be the focus of separate studies.

Definition of Terms

Social networks are the web of social ties which surround an individual (Berkman, 1984). These networks are comprised of members who fulfil a formal role (eg., nurses, physicians, social workers) or an informal role (eg., family, friends, self-help groups, church groups, (Dunst, Trivett, & Deal, 1988).

Social support is defined as the resources that are provided by the social networks. These resources are of the following types: a) emotional support (esteem, affect, trust, concern, listening); b) appraisal support (affirmation, feedback, social comparison); c) informational support (advice, suggestion, directives, information); and d) instrumental support (aid in kind, money, labour, modifying environment)(House,1981).

Caregivers are those persons who assume primary responsibility for a dependent, cognitively impaired older person. The degree of care given may include physical care, but caregiving is not contingent upon this aspect. It is also not necessary that the caregivers live with the cognitively impaired adults. The caregivers in this study are women who are related to the care recipients either by birth or by marriage.

Purpose of the Study

The purpose of this study was to describe the social networks and the types of perceived support described over time by women who are caregivers

of cognitively impaired older adults. The nature of the caregivers' social networks were examined by analysis of their descriptions of their social networks and perceptions of support. Emphasis was given to the analysis of the women's informal network and perceptions of satisfaction with support from this source.

Research Questions

1. How do caregivers of cognitively impaired older persons describe their social networks and the variations in these social networks?
    - 1.1 Who are the members of the social network including both informal and formal sources of support)?
    - 1.2 How are the members of the informal social network described, including their relationship to the caregiver?
    - 1.3 Who are the sources of support utilized by the caregivers?
    - 1.4 Who are the available sources of support which are not utilized?
    - 1.5 Who are the sources of conflict within the social network?
2. What types of support does the caregiver perceive to be present or lacking (eg.,affective, instrumental, informational and appraisal) and how do they vary over time?
3. What is the caregivers' perceived satisfaction with the support received from the social network and how does it vary over time?

4. What, if any, are the common variations in the caregiving experience which may influence social networks and social support? Factors such as the context in which the caregiving takes place (i.e., home or long-term care facility), the relationship of the caregiver to the older adult, and other responsibilities of the caregiver will be considered.

Chapter 2

Literature Review

Perceived support has been associated with the health status of caregivers. Social networks are the structures through which social support is provided. Because inadequate social networks can result in limited support they are an important phenomena to study. The following review of the literature addresses social networks and social support in relation to the context of caring for a cognitively impaired family member.

Social networks, Social Support and Their Relationship to Health

Social networks and social support are complex and multidimensional concepts. There have been numerous attempts to measure them, by both objective and subjective means. The association of social support with the well-being of individuals has also been explored. Although the problems of caregivers have been well documented, there has been limited research on the characteristics of the networks of caregivers and on the types of support that they receive.

House (1987) points out that there is no agreement on the measurement and conceptualization of social support, and that the term has been frequently used interchangeably with social network. He contends that social networks are measures of social structures while social support is measured in terms of

psychological sentiment. There seem to be relatively few studies which include measures of the two concepts. This results in a lack of understanding of the relationship between social support and social networks and the manner in which the two may affect levels of stress, health, or even the relationship between stress and health.

Although social networks and social support have been of interest to researchers for a number of years, the 1970's heralded an increasing number of studies which identified their relationship with health. Cassel (1976) highlighted the importance that social support plays in the well being of an individual when he investigated the relationship between health problems and urban environmental conditions. He concluded that the disruption of social ties that can occur under stressful conditions increases susceptibility to disease. Therefore, the strategy for protecting health would be to mobilize social support. Weiss (1974) discovered that the absence of a social network, with shared central life concerns, results in individuals experiencing severe life distress. Others concurred with the findings that the accumulation of life stressors increases a person's vulnerability to disease in general (Gottlieb, 1985) and that social support provides resources for successfully dealing with stressful situations (Eckenrode & Gore, 1981).

The mechanisms by which social networks provide social support and

have an effect on health are not clearly understood or agreed upon by the various theorists. Some postulate that social networks may influence health outcomes by either providing support in the form of necessary information or by enhancing the incentive to engage in healthy behaviours (Bloom. 1990). Networks may provide social support in the form of aid, services and tangible or economic support, which can have an immediate effect on a person's health status. Social networks also provide a sense of intimacy and belonging, the opportunity for nurturing and a feeling of worth. The lack of these provisions may result in an individual who is physiologically stressed (Berkman, 1984). Social networks may assist or foster behaviours which are promotive of health or which may protect the individual's health when faced with stress or other health hazards (House, Umberson, & Landis, 1988).

Social Networks

Support is provided through an individual's social network, which is the web of social ties that surround an individual (Berkman, 1984). These ties can be continuous or intermittent and play a significant role in maintaining the physical and psychological integrity of an individual (Caplan, 1974), by providing emotional support, material aid and services, information and access to new social contacts (Walker, McBride & Vachon, 1974).

When analyzing social networks, it is important to consider the

characteristics of the network. Walker et al (1974) have described these characteristics as follows.

1. Size. This refers to the number of people with whom an individual maintains some social contact, including those contacts which can be renewed in case of need.
2. Strength of ties. This refers to a combination of characteristics such as the amount of time, the emotional intensity, the mutual confiding, and the reciprocal services which characterize the tie.
3. Density. This is the extent to which the members of the individual's social network know and contact one another independently of the individual. High density describes a network in which a high proportion of all possible independent contacts are in fact made; low density describes one in which a low proportion are made.
4. Homogeneity of membership. This is the extent to which network members share social attributes, including demographic characteristics such as age, sex, ethnicity and social culture, and attitudinal and behaviourial characteristics such as social values and life styles.
5. Dispersion of membership. This is the ease with which network members can make face-to-face contact. This is a function of

geographic distance as well as adequate transportation.

Chappell and Blandford (1991) studied the social networks of persons 65 years and older. They viewed social networks as being comprised of informal and formal support systems. Their correlational study looked at dependent variables such as: no support received, informal support only received, formal support only received, informal and formal support received but separate areas, informal and formal support received in the same areas of activities of daily living. Independent variables were health and informal support. Informal support was defined using network characteristics including the number of children, relatives and household members, the number of friends and neighbours, and the presence and/or absence of a spouse. No mention was made of how issues of conflict were dealt with or if caregivers were satisfied with the support received.

A framework of support by Israel, Hogue and Gorton, (1984) looks at the structural characteristics, (such as size and density), the interactional characteristics, (such as directedness, reciprocity, frequency, homogeneity and dispersion), and the functional characteristics (such as instrumental and affective support). Though fairly comprehensive, this framework does not address issues such as conflict, perceptions of support and satisfaction with support received.

This brief review of network analysis indicates that there has been a lack of unanimity in describing social networks, though there are points which are similar. Although there has been considerable research conducted in this area, there is no real consensus about the components which are characteristic of all social networks.

Social Support

Social support is viewed as the exchange of resources between at least two individuals with the intention, as perceived by provider or recipient, to enhance the well-being of the recipient (Shumaker & Brownell, 1984). It refers to a number of different aspects of the social relationship and is defined in terms of the existence and quality of relationships (House & Kahn, 1985). Social support serves to validate an individual's identity through feedback about behaviour and assists in the mobilization of psychological and physical resources (Israel, 1982). Social support has been defined as that which lead people to believe that they are cared for, loved, esteemed and valued and that they belong to a network of communication and mutual obligation (Israel, Hogue & Gorton, 1984). The presence of social support in an individual's life can be related to that individual's style of coping, a lack of other related resources or the prior occurrence of certain life events (Hobfoll, 1986). This would suggest that a need for and utilization of social support in the past

influences an individual's use of social support in future situations. Gottlieb (1983) states "... an individual's past experience in dealing with a given stressor also ought to constitute an advantage when the same or a similar stressor is introduced again" (p.34). Perhaps more importantly, the structure of the social network, and needs of the individual, partially determine the specific types of support that are either sought or offered (Dunst, Trivett, & Wunst, 1988).

Various frameworks have been used to examine social support. Tardy (1985) developed a framework which uses five categories to explore social support. The first category is direction, in that social support is both given and received. The second category is disposition, which refers to the both the availability of support (quantity and quality) and to the actual utilization of the support. The third category is description/evaluation, which involves the description of the support as well as the individual's satisfaction with the support received. The fourth category is content, which is composed of four components; emotional support, instrumental support (eg. helping behaviours), informational support, and appraisal support (eg.evaluative feedback). The fifth category is network, which considers the characteristics of the persons in the support network. This framework does not address the issues of conflict, nor the duration of support required or received, both of which have important effects on a caregiver's well-being.

Another framework is one that resulted from a study by Norbeck, Chaftez, Skodol-Wilson and Weiss (1991). This study looked at support needs of family caregivers of psychiatric patients. The researchers developed a typology of support needs expressed by these caregivers. The categories of support needs that emerged from this study were: emotional support (eg., acceptance, commitment, social involvement, affective and mutuality), feedback support (eg., affirmation, listening, and talking), informational or cognitive support (eg., illness information, behaviour management, coping, decision, and perspective), and instrumental support (eg., resources, respite, care-help, backup and household). Although all of these categories are important when considering social support, the perceptions of conflict and satisfaction with support received are not addressed by this framework.

As was the case for social networks, the elements of the different frameworks used to examine social support are very similar. Again, confusion can result due to a lack of consensus on how to conceptualize social support. This lack of unanimity in describing social support can lead to difficulties in the generalizability of results of the studies on social support.

The Obligations of Social Networks

Belonging to a social network carries with it the implication of a mutual obligation that is a result of the exchange of resources and the understanding

that acceptance of a benefit places the recipient in a state of indebtedness (Shumaker & Brownell, 1984). This sense of obligation and indebtedness has implications for an individual accessing support from the social network. There are costs related to the maintenance of relationships in the reciprocal exchange of time, energy, goods or services (House, 1981). It has also been shown that the level of social support and level of functioning is related to the degree of reciprocity in the relationship (Bruhn & Phillips, 1984.) Often individuals see themselves as being the recipient of support beyond what is deserved or can be repaid. Situations such as this may result in the positive effects of the support being reduced or eliminated (Kahn & Antonucci, 1980).

The Negative Aspect of Social Support - Conflict

Another important aspect of social support is that social relationships may not always have a positive impact on the caregiver. The results of some research has shown that some sources of social support may actually cause conflict for the caregivers. Tilden & Stewart (1985) note that historically, there had been an absence of any attempt to measure the costs and stresses associated with social support. A request for help may be seen by some as embarrassing and demeaning and can have repercussions on an individual's self-esteem (Hobfoll, 1986). Some experts feel that over-involvement or under-involvement of family members can lead to negative adaptive outcomes. The

effects of over-involvement can lead to interference with problem solving, if members become too focused on their efforts to help. Other family issues may begin to take precedence over the concerns of caregiving (Coyne, Wortman & Lehman, 1988).

These issues need to be considered when looking at the needs of caregivers of the older persons. It is critical to realize that some sources of social support may not always have the desired effect and may cause the caregivers more stress than benefit. It is important not only that the caregivers receive the full amount of support available, but that the type of support they receive will be beneficial.

Caregivers and Caregiving

Many studies have examined the effect that caregiving has on caregivers. Caregivers have less time to spend on hobbies or other relaxing activities and are less able to participate in social functions (George & Gwyther, 1986; Given et al, 1990; Hogan, 1990). There is often the perception of a need for more assistance from friends and relatives. In many cases, the demands of caregiving have resulted in the withdrawal of other family members from interacting with the caregivers themselves and from the family member needing care (George & Gwyther, 1986; Given et al, 1990). Caregivers often assume roles that they have not been prepared for. They may need to

perform health care measures for which they have not been trained and may have unrealistically high expectations of themselves (Given et al, 1988; O'Neill & Ross, 1991).

Elderly women who are caring for spouses or other family members are often entering a period of life when they themselves are experiencing a diminishing number of personal or social contacts (O'Neill & Ross, 1991). This can result in the loss of potential sources of assistance to meet their own needs and those of their dependent spouses or relatives.

Nolan and Grant (1989) contend that addressing the needs of informal caregivers has been a neglected area of nursing practice. They conducted a sample survey of national caregivers through the inclusion of a postal questionnaire with a newsletter of a caregivers' group. The questionnaire included a measure of care stress and a carer-perceived problem checklist. The study received a response of 671 questionnaires. The results of the data analysis suggest that the objective circumstances of caring contribute only a small part to caregiver stress and that the emotional elements are more significant. The largest single problem identified in this study related to poor professional attitudes. Other problems were the provision of insufficient or inappropriate help and a failure to provide relevant information and advice.

Caregivers of Cognitively Impaired Older Persons

The impact of caregiving on caregivers of cognitively-impaired older persons has been studied in some depth. Studies have shown that the major effects of the caregiving burden have been in the area of mental health, social participation and to some extent financial resources (George & Gwyther, 1986; Hogan, 1990).

In a comparative study by George and Gwyther (1986), the well-being of family caregivers of cognitively impaired older persons was examined in four dimensions and compared with the well-being of a community sample. The dimensions were physical health, mental health, financial resources and social participation. Five hundred and ten caregivers were studied using several assessment tools. The results indicate that in comparison with random community samples, caregiver burden is experienced primarily in areas of mental health and social participation. This study showed that caregivers averaged three times as many stress symptoms as did the comparison group. Twenty-eight percent used psychotropic drugs in comparison to 19 per cent of non-caregivers. A limitation of this study is that it addressed caregivers' perceptions of well-being at one point in time, and did not address the caregiving situation over the course of time.

The caregiver's greatest difficulties are lack of time for oneself, the

dependency of the care recipient on the caregiver, and the caregiver's fear about the future deterioration of the person receiving care (Jenkins, Parkham, & Jenkins, 1985). Several of the characteristics of cognitive impairment contribute to the social isolation of the caregiver. Many cognitively impaired persons are reluctant to leave the confines of their homes, or are so dependent upon their caregiver, that they inhibit the caregiver from partaking in any sort of social intercourse. There are practical limitations as a result of incontinence or immobility, and the embarrassment felt by the caregiver related to the often "socially-unacceptable" behaviours that can be characteristic of persons with a cognitive impairment (Brodaty & Hadzi-Pavlovic, 1990).

Brodaty and Hadzi-Pavlovic (1990) were interested in the psychosocial effects on caregivers of living with persons with dementia. They surveyed the members of a self-help group for caregivers of persons with dementia, asking them to fill out a questionnaire which looked at the socio-demographic characteristics of the caregiver and care recipient, length of time as caregiver, current living arrangements and various measures of depression, health status, and the cognitively impaired persons' behaviour and degree of dementia. An overview of the results of the 146 responses indicated that a) the level of distress of the caregivers, though high, was not as high as reported in previous studies, b) caregivers of spouses suffer more psychological distress than did

other caregivers, c) problem behaviours have a noxious effect on the caregivers' general psychological health, and d) that dementia of the person receiving care has an isolating effect on the caregivers. This results in the existence of a subgroup of vulnerable caregivers, who are characterized by psychological, physical and social morbidity. The researchers noted that a limitation of the study was that the those who did respond may have been psychologically healthier than those who did not, though a significant proportion of non-respondents were health professionals and not family caregivers.

Social Support and Caregiving

Baillie, Norbeck and Barnes (1988) were interested in the effects of stress and social support and their interaction with the psychological well-being of 87 family caregivers of impaired elderly persons. The results of this correlational study showed that only two conditions of caregiving were found to be significant predictors of psychological distress. They are: years of caregiving and the mental condition of the elder. Caregivers of mentally impaired elders, who have been providing care for a long period of time and have low social support are at risk for psychological distress. Unfortunately, the ability to generalize from this study is limited by the non-random, and mainly middle-class nature of the sample. Furthermore, as the authors indicated, the instruments used to measure perceived stress (a 16-item questionnaire designed

for the study) and satisfaction with social support (an 8-item questionnaire designed for the study) have internal validity, but need to be more fully developed to ensure external validity.

Norbeck et al (1991) were interested in the social support needs of family caregivers of psychiatric patients from three age groups: children, adults and older persons. Interviews of 60 family members were analyzed by developing a set of thematic categories. The researchers discovered that although the support needs expressed paralleled those delineated by House (1981) (ie., emotional, feedback, informational, and instrumental), the specific meaning of support was tied to the caregiving role. Each group of caregivers had needs unique to their caregiving role, as well as some needs in common. The importance of these needs often differed from the needs of caregivers of non-cognitively impaired dependents. Because the sample was small, predominantly white and middle-class, and limited to specific disease categories, the ability to generalize the results is limited.

Conclusions

As this literature review indicates, there has been much interest and considerable research in the areas of social support and social networks. Studies have chronicled the relationship between positive support and the abilities of persons to face stressful or crisis situations. The effects that caring has on

caregivers have also been well documented, especially for those who care for persons with some degree of cognitive impairment.

If we are to assist caregivers to access the optimal level of support required, we need to conduct more specific research that focuses on the characteristics of the caregivers' social networks and the types of support they receive. Qualitative studies provide detailed information about the caregivers' perceptions of their social networks, which is not available from the use of quantitative measurements. Understanding of the components of caregivers networks with which they are satisfied and dissatisfied is also necessary, in order to focus on those areas where intervention is required.

Chapter 3

Research Method

Qualitative research methods were employed in this study in order to gain access to information about the social networks of women caregivers from an emic perspective. This method of research allowed the researcher to obtain a multidimensional view of these social networks, without the constraints of confining measurements or experimental controls being placed upon the phenomenon being studied (Field & Morse, 1985; Patton, 1990).

Data Generation

This study involved secondary analysis of data provided by a group of women caregivers of cognitively impaired older adults. The women were interviewed in an earlier study of perceptions of support and reciprocity while caregiving (Neufeld & Harrison, in press). A thematic form of content analysis was used to examine the transcripts of the semi-structured interactive interviews regarding the women's descriptions of their social networks. Ecomaps and the results of the Arizona Social Support Inventory Schedule (ASSIS) were also examined.

In the original study 20 caregivers were interviewed for approximately one hour, from three to four different times over a period of eighteen months. (See Appendix A for interview formats). Respondents were volunteers

recruited through advertisements in health care agencies and community groups or local publications. The initial interview asked the respondent to describe her perception of social support and reciprocity within her social network and caregiving relationship. Subsequent interviews focused on changes in the caregiving relationship or other relationships over the eighteen months. During the final interview, questions that arose from the previous interviews and analysis of the data were reviewed and the Arizona Social Support Inventory Schedule was completed to obtain a description of the available and utilized social support.

The ASSIS (Barrera, 1981) is a structured interview schedule which is used to measure several aspects of social support. Areas examined are (a) private feelings, (b) material aid, (c) advice, (d) positive feedback, (e) physical assistance, (f) social participation, and (g) negative interactions (see Appendix B). The women were asked for their perceptions of satisfaction with the support they received. Respondents were also asked to provide some demographic data about the people whom they named as being sources of support. Data obtained from this schedule provided information about the available, utilized and conflicted network. Demographic data was collected on all of the caregivers (see Appendix C).

EcoMaps were also completed by the researcher at the end of the first

interview and updated during the course of the study, to provide a visual representation of the caregiver's social network, and to show changes over time. Ecomaps are a pictorial representation of the social network created by the researcher to depict the transactional relationships between the caregiver and the environment. They focus on the sources of support from the intimate and extended social environment (Hartman, 1979). Ecomaps demonstrate the flow of resources from the environment to the individual as well as the deprivations and unmet needs, stresses and available supports (Holman, 1983). (See Appendix D.)

Data Analysis

Data Analysis Methods

Initially all the transcripts for each caregiver were read in a consecutive order. This process served to immerse the researcher in the data and gave her a sense of all the components that characterized the caregivers' social networks. A diary was kept to record initial impressions and ideas during this process. This aided in the subsequent analysis of the data and also helped the researcher keep track of biases that she may have brought to the study.

The next step was to compose a profile of each caregiver and their care recipient, including a summary of their caregiving experience. These profiles were referred to frequently in order to maintain a clear picture of each of the

caregiving situations.

The interview data was then analyzed using thematic content analysis. The research questions provided a frame of reference from which the data was studied in order to identify emerging themes. The information sought related to the structure of the social network, the sources of available and utilized support, and the sources of conflict. Information about satisfaction with informal support received was also identified as well as variations over time. The researcher used a code-recode process when looking at themes. This was accomplished by looking at the data for various themes, then waiting a period of time and re-analyzing the same data to ensure that the themes which emerged initially were also apparent on re-analysis.

The Ethnograph computer program (Seidel, Kjolseth & Clark, 1985) was used to help in the process of organizing and retrieving coded data, and to compare themes across interviews or across respondents. Its use also facilitated the examination of themes which appeared to be related. As the Ecomaps are not a source of raw data, but are rather the synthesis of data already collected, their value was in providing the researcher with an immediate picture of the caregivers' social networks as a whole, as well as any changes that may have occurred over time.

The women's responses to the Arizona Social Support Inventory

Schedule (ASSIS) served to validate the information given in the interviews. It also provided some additional information regarding the social networks and support received. The ASSIS provided systematic means of accounting for perceived sources of support, utilized sources of support, and sources of conflict and satisfaction, which may have been inadvertently omitted during the interviews. The ASSIS also included information about the characteristics of the members of the social network which may not have emerged during the interview. The ASSIS, however, only looked at the social networks at one point in time, and did not give a full picture of the continuum of the caregiving experience. It was utilized to give a comprehensive description of the caregivers' social networks as they existed at the end of the study.

After the social networks of each caregiver had been examined in detail a typology of social networks was developed. This typology was based on the membership of the social networks, characteristics of the individuals within the social network, the presence of conflict, and the caregivers' satisfaction with the support that they received.

The data were then re-examined to determine if there were any variations in the caregiving context that may have influenced the characteristics of the social networks and perceptions of social support in relation to the identified network typology. Finally, the relationship of the caregiver to care

recipient, residence of the care recipient and other responsibilities of the caregiver were all explored in order to give some further dimensions to the caregiving context.

Reliability and Validity

Guba (1981) has outlined four criteria that are relevant to evaluate the trustworthiness of qualitative research. These four criteria are credibility, transferability, dependability and confirmability and will be described below in relation to this study.

Credibility

Addressing the issue of credibility also addresses internal validity. Information was collected from the caregivers in three or four in-depth interviews over a period of 18 months. This time span allowed for changes in the caregivers' perceptions of their social networks, for the caregivers to become familiar with the interviewer and for the interviewer in later interviews to confirm some statements made earlier by the caregiver. Although this researcher was not able to validate her findings with the caregivers in order to strengthen credibility, she was able to discuss her analysis of the data with the original researchers.

Confirmability

The issue of confirmability is one of internal validity and is addressed by the use of triangulation of data sources. The collection of data from interviews and ASSIS and corroboration from the Ecomaps allowed for the cross-checking of data and interpretation. Internal validity (and confirmability) was also addressed by having members of the thesis committee, who were the original researchers, audit the data analysis process.

Transferability

The interactive interviews that were conducted with all the caregivers provided a rich description of their social networks and caregiving situations. This allows other researchers to compare the characteristics of the caregivers' social networks in this study with other possible groups. External validity is therefore addressed in terms of being able to identify the potential to transfer the results of this study to similar situations (LeCompte & Goetz, 1982).

Dependability

Krefting (1985) suggests that dependability can be increased by conducting a code-recode procedure on the data. This is accomplished by coding the data and then waiting a period of time before returning to recode the data. Triangulation of data collection methods (such as interviews and ASSIS) contribute to the dependability of the study by allowing for examination of the

consistency of information from each caregiver (Krefting, 1991)

Ethical Considerations

Both the original study and the present study were conducted in accordance with the regulations for ethical acceptability of the Faculty of Nursing of the University of Alberta. This researcher had access to the transcripts of the interviews, Ecomaps and the ASSIS questionnaires which were kept in a locked filing cabinet. This researcher had no knowledge of the identity of the respondents.

Chapter 4

Findings

The purpose of this study was to describe the social networks of women who are caregivers of cognitively impaired adults. Content analysis of the women's descriptions of the sources of support was done to understand and interpret the women's perceptions of their social networks. Perceived satisfaction with the support received was also explored. Any variations over time were noted. A typology of social networks for this group of caregivers was identified after content analysis of all of the data.

The three types of data together provided a rich description of the caregivers' social networks. The interviews gave the most information. This may be because the ASSIS was completed at one point in time and is comprised of structured questions to which the informants responded by selecting the statement most accurate for their relationships. The Ecomaps were drawn by the researcher with input from the caregiver at the end of the interview and revised following subsequent interviews. As diagrammatic portrayals of the network, they were less encompassing than the interviews.

The Study Sample

The sample for this study was comprised of twenty female caregivers of cognitively impaired older persons. All 20 caregivers remained in the study until its completion, although three of the care recipients died during the course of the study. The caregivers ranged in age from age 37 to 71, educational level from less than grade 12 to university education, and varied in levels of household income. The characteristics of this group of caregivers, at the time that they entered the study, are described in below in Table 1.

Table 1.

Sample Characteristics (n=20)	
Age in Years	
35-50 years	3
51-65 years	13
over 66 years	4
Years of Caregiving	
0-5 years	5
6-10 years	3
11-20 years	10
over 21 years	2
Education Level	
< than grade 12	5
grade 12	2
post secondary	7
university	6
Income Level	
< $20,000.	3
$20,000.-40,000.	7
> $40,000.	10
Relationship to Care Recipient	
wife	8
daughter (in-law)	11
other kin	1
Employment Status	
employed: full-time	6
employed: part-time	2
not employed	12
Marital Status	
married	
to care recipient	8
not care recipient	9
not married	3
Other Caregiving Responsibilities	
yes	6*
no	14

* included the women's children, grandchildren and other responsibilities

Membership of Social Networks of Caregivers

Caregivers identified informal members (such as friends, relatives, neighbours, colleagues etc) as belonging to their social networks more often than formal members (providers of various services). Relatives, friends and neighbours were the predominant informal members. Other frequently mentioned informal members were social and recreational groups and work colleagues. The most frequently identified formal members of the social networks were family physicians, homecare staff and long term care staff. Other formal members were government agencies, societies (such as the Alzheimer's society) and support groups.

For the purpose of this study, those care recipients who lived in long term care facilities were identified as LTC residents. Those care recipients who lived with their caregiver or in their own dwelling were identified as non-LTC residents.

Variations in Membership Over Time

Most caregivers did not identify much variation in the membership of their social networks over time. A common observation of some caregivers, was that the longer the caregiving relationship lasted, the more likely a few members would lose interest or lose touch with the caregiver and/or the care

recipient.

> *...as she had deteriorated, the kids are less willing to be around...*

Some of the caregivers actually extended their social networks over the course of the caregiving relationship, as they met people in support groups that they joined, or through the formal and informal institutions with whom they had interactions.

> *I founded them [a caregiver support group] because I felt I needed help myself...*

A few of the caregivers, having lost some of the social interaction previously enjoyed with the care recipient, found themselves joining new social groups in order to experience some type of a social life outside of the caregiving relationship.

> *...I've started going out more. I think that I'm the one now that has to make friends.*

Other caregivers may have experienced less frequent contact with certain members of their social networks, (eg. in the circumstance when a child moved away) but did not lose these persons as members of their networks.

> *...my son still phones home every two to three weeks; my daughter can't afford to phone,....but she does try to write regularly.*

Sources of Support

Support Available and Utilized

Caregivers of LTC residents availed themselves of more support sources than did the caregivers of non-LTC residents, despite the fact that the caregivers of non-LTC residents often had to provide more physical care. The largest group utilized by both group of caregivers was friends. Both groups depended upon their spouses and children, while in-laws, siblings and recreational groups were used more often by caregivers of non-LTC residents. The family doctor was utilized as a source of support by both groups of caregivers, as were support groups.

Variations in Support Over Time

For the most part, the caregivers did not notice any significant changes in the support that they received over time. Two of the caregivers found that their spouses were less willing to assist them with their caregiving role as time went on, as the spouse felt that the care recipient was either too demanding and/or required too much of the caregiver's time. For example, the husband of one of the caregivers became impatient with the care recipient who demanded a considerable amount of attention.

> *...and yet the last while he's been saying, "well, you know she stopped her own trips out with the cab...and expects you to take over from there". He felt that wasn't right,either.*

Some caregivers noticed a slight increase in support, often in terms of friends or family members becoming more aware of the realities of the caregiving situation and developing a better understanding of the emotional and physical burden placed on the caregiver. Often these persons were already sources of support, but came to increase the amount of the support that they gave to the caregiver and care recipient.

> *My own children have become better, like they were really good at first, but now more things are fitting in..*

Some caregivers noted a slight decrease in support for a variety of reasons. Some of the caregivers had a member of their social network move away from the area and therefore was not readily available, especially in terms of providing physical support. A few caregivers experienced situations where a member of the social network became ill or had to assume a caregiving role themselves and therefore were not in a position to continue to provide support.

> *And one friend that used to go and see my mother, she has cancer...so she doesn't go up as much as she did before.*

In a couple of instances the network member died.

> *...just a week ago.. I lost my wonderful neighbour.. He cut my grass and did all these wonderful things..what a support he was for me...*

None of the caregivers indicated that other members of their social networks emerged to assume a role similar to that performed by the person who was lost

from the network.

Support Available and Not Utilized

Sources of support can be available to the caregiver but are not utilized for a variety of reasons. When examining the support available and support utilized, it is difficult to differentiate between the two when using the interview data. This is because rarely did respondents mention support that was available but not utilized, as this was not one of the questions asked in the original research study. For the most part the only information available on this question is the response given to the ASSIS question which addressed this issue. Both groups of caregivers identified friends, various types of relatives, co-workers, recreational groups and church members as being available for support but at times not utilized. Caregivers identified homecare and the family physician as the only available but at times non-utilized formal support sources. There were no reported variations over time.

Sources of Conflict

Social networks are not only sources of support but can also be sources of conflict. Throughout this study it was established that often persons who were sources of support could also at times be sources of conflict.

When looking at the interview data, formal sources of support (such as homecare, long term care staff and family physicians) provided instances of

conflict far more often than did informal network members (such as relatives, friends, care recipients and neighbours).

However, the Ecomaps and ASSIS named informal members as sources of conflict much more frequently than they did formal members of the social network. It is important to note here that formal members were rarely identified as being part of the caregiver's social network on the ASSIS and only a little more often on the Ecomaps.

Conflict, on the basis of the caregivers' descriptions in the interviews, is classified into six different categories: anger, dissatisfaction with care received, dissatisfaction with assistance received, disagreement, lack of concern and non support. As described below, some conflict resulted from interactions with informal members of the support network (such as relatives), and some conflict was the consequence of exchanges with formal members of the network (such as physicians, long-term care staff and homecare staff).

Anger

Anger was a stated emotion experienced by the caregiver as a result of a network member's actions or attitudes towards either the caregiver or care recipient. The caregiver had to actually identify anger as the type of conflict experienced in a particular incident for it to be classified as such. Anger was experienced in only a few instances and was engendered by both informal and

formal members of the social network. For example, a granddaughter caring for her grandfather made the following comment about her grandmother.

> *She could afford to give him [the grandfather] any lifestyle he wanted [but did not] ... and that made me really angry.*

A daughter experienced anger when dealing with the staff of a long term care facility.

> *A lot of anger because...I had asked them [the long term care staff] to call the doctor and they said he didn't come. (but in reality they had not called him)*

Dissatisfaction with Care Received

This type of conflict was identified from the interview data by the caregivers' statements that demonstrated their displeasure with care given to the care recipient by network members. Caregivers frequently reported this type of conflict when interacting with formal caregivers such as homecare, long term care staff and physicians.

One caregiver was dissatisfied with the physical care that her relative received in a long term care facility.

> *Sometimes he was not very clean.*

Another caregiver had to often accompany her husband on emergency trips to the hospital as a result of his condition. On one occasion the caregiver was displeased with the attending physician's attitude towards her husband.

The doctor that he saw this time kept saying that his days are numbered.

Dissatisfaction with Assistance Received

Caregivers indicated the presence of this type of conflict when they complained about the degree or quality of support that they (the caregiver) received from formal network members such as homecare and government agencies. This support was either instrumental in nature (eg., housekeeping assistance) or of a financial nature (eg., pensions).

One caregiver needed her husband's bed raised so that she would be better able to care for him.

..and one of the homecare nurses brought three blocks for a bed that has four legs.

Another caregiver was frustrated in her attempts to obtain the resources that she needed to care for her husband at home.

There is no one to help the disabled. (talking about the government).

Disagreement

This type of conflict was the result of disagreements between the caregiver and a network member concerning the other's actions towards the care recipient or differing beliefs about caregiving responsibilities . This was a common type of conflict involving informal members of the social network, and was not experienced with formal members of the social network.

She [the grandmother] talks about him in the third person when he's there. (caregiver does not agree with this treatment of the care recipient)

..my husband wasn't really for that. (discussing having mother come to live with them)

..and I know that my brother was very upset at me putting her in [the LTC facility].

Lack of Concern

Caregivers found that lack of concern was the most common type of conflict experienced when dealing with informal members of the social network, such as family and friends. The lack of concern was with regards to either the well-being of the care recipient or the support needs of the caregiver. There were also instances of lack of concern on the part of formal members such as family physicians and homecare and long term care facilities.

[Homecare] are just not interested in the people at home.

I suppose with my sister concern was lacking there.

But I found the nursing home uncaring about other things.

..when I phoned my brothers nobody seemed to care. [about her concerns regarding their mother]

So I called the doctor. He promised to see her but didn't go.

Nonsupport

In the original study, the caregivers were asked whether or not they had ever experienced nonsupport in their caregiving experience; nonsupport to be defined by the individual caregiver. It was a common type of conflict that caregivers experienced from a variety of informal sources, but not from formal members of the social network. The following comments are from caregivers discussing their family in direct response to the question on nonsupport.

> *I feel that they are not involved at all.*
>
> *And to me I've got nonsupport in what I've asked for.*
>
> *..she's never come to visit. (Discussing a sister who never comes to visit their mother, thus relieving some of the burden.*

Variations Over Time

For some caregivers, the experience of conflict was an isolated incident. For example, one caregiver's sister was usually a strong source of support, except in a single instance when she was not willing to assist the caregiver. In other situations, the conflict may have lasted over a period of time, but was finally resolved. This happened to two of the caregivers who, over a period of months, were in conflict with their daughters-in-law. In both situations the caregivers were able to resolve the conflict with their daughters-in-law.

One caregiver experienced almost constant conflict with members of her social network, but there were rare instances when these members were actually short-lived sources of support. This caregiver had her grandfather living with her, as her grandmother was unwilling to assume the caregiving role any longer and wanted the grandfather placed in a long term care facility. The grandmother normally did not support the caregiver in her decisions, and was a constant source of conflict. There were infrequent instances, however, when she did provide support, mainly in the form of money or agreement to a certain plan.

However, there were also situations where the conflict was continuous, as was the experience of many caregivers whose older relative was either in a long term care facility or resided at home but required the services of homecare. In many of these situations, the conflict was always present, as the caregivers were constantly dissatisfied, either with the care that was given to the care recipient or with the assistance that was given to the caregiver to help them in their role. For example, one care recipient was prone to bladder infections that made her quite ill. However, it was her daughter who had to repeatedly prompt the staff of the Long term care facility to check her mother's urine, whenever the daughter noted that her mother was exhibiting symptoms of a bladder infections. This constant presence of conflict was difficult for the

caregivers as these sources of conflict were also sources of support at the same time in that they did provide some service or care to the care recipient or caregiver.

Typology of Networks

A typology of the networks of the women caregivers was identified after extensive analysis of the interview data, ASSIS data and Ecomaps. Three distinct types of networks emerged: diverse networks, semi-diverse networks and kin-dominated networks. Nine caregivers had diverse social networks, seven caregivers had semi-diverse social networks and the remaining four caregivers had kin-dominated social networks. Table 2. depicts the characteristics of the network typology.

Table 2.

Typology of Social Networks

TYPE OF NETWORK	Diverse	Semi-diverse	Kin-focused
SIZE	large	medium	small
RANGE OF MEMBERS	widely varied	somewhat varied	limited
NETWORK MEMBERS	recipient relatives friends formal members support groups social groups church colleagues local business	recipient relatives friends formal member support groups social groups	recipient relatives friends formal members support groups
PROXIMITY OF NETWORK MEMBERS	some close some far	some close some far	all close none far
INTERCONNECTEDNESS	varied	varied	connected
CONFLICT	occasional small amount	fairly frequent moderate amount	frequent large amount
SATISFACTION OF CAREGIVER	mainly satisfied	some satisfied	none satisfied

Diverse Networks

Diverse networks were large and varied (ranging from 15 to 20 members) and were composed of a rich mixture of relatives, friends, colleagues, social groups, support groups and many other informal and formal members. Eight of the nine caregivers who had this type of social network

were totally satisfied with the support that they received from their social network.

Semi-Diverse Networks

The semi-diverse network had a medium number of members (ranging from 8 to 14 members) and was only slightly varied. The majority of members were relatives and friends, but there were a small number of other members, such as support groups and some formal members. The perceptions of satisfaction with support received by this type of network were: three were satisfied and the four other caregivers were dissatisfied with the support provided by their network.

Kin-Focused Networks

The kin-focused network was small and limited (from 5 to 8 members), made up primarily of relatives and some friends. In rare instances, other persons such as members of a support group or another type of group were identified. There were some formal members also. None of the four caregivers with this type of network were satisfied with the support that they received.

Recipients of Support

The results of the data analysis indicated that support directed towards the caregiver, the care recipient, or both the caregiver and care recipient, was of direct benefit to the caregiver. The support directed to the caregiver occurred

in about half of the instances. This support was actual physical assistance, (i.e. maintenance of home and garden, housekeeping chores or other helping acts), or emotional support, that bolstered the caregiver psychologically and helped to moderate some of the effects of the stress caused by the caregiving relationship. Financial or informational support was also provided to the caregiver.

Support directed towards the care recipient was usually actual physical care, or in the form of visits or outings. Support that was directed towards both caregiver and care recipient was in the form of physical assistance, as visits or other social excursions, and/or emotional support aimed at both the caregiver and care recipient.

Types of Support Present

The types of support that were present are identified by the types of support that are utilized. In reviewing the interview data, it was evident that the types of support described by the women caregivers were consistent with those characterized by House (1981), and these categories of support are used to organize the presentation of information from the women's descriptions of support discussed in this study. They are instrumental, emotional, appraisal and informational support.

Instrumental Support

Instrumental support is comprised of labour (eg., physical care or housekeeping), aid-in-kind (eg., visits or outings), money and modification in the environment (eg., installation of bathroom aids). Informal sources of support provided instrumental support twice as frequently as did formal sources of support. Some examples of the women's descriptions of perceived instrumental support follow.

> *[The hospital] took good care of him, anytime I came someone was with him. And they made him walk again, like on a walker. (LABOUR)*
>
> *..and this one lady was not very nice to mum and so they [the Long term care staff] made sure that she got out of that room and promised that it would never happen again. (MODIFYING THE ENVIRONMENT)*
>
> *...well I should say that the money that was put into the car was paid by the kids, I didn't have it. (MONEY)*
>
> *The minister at our church often drops by in the evening to sit and watch the game with [my husband]. (AID-IN-KIND)*

Emotional Support

Emotional support was utilized frequently by caregivers. Informal sources provided this type of support twice as often as did formal sources of support. Emotional support is comprised of concern, listening, fostering esteem, showing affect, and demonstrations of trust in the caregiver. Concern was expressed by inquiring about the health of the caregiver or care recipient,

expressing anxiety that perhaps the caregiver was over-extending herself, and other similar expressions. Listening allowed the caregiver to discuss her concerns and fears. Words or actions that demonstrated that the network member respected and admired the caregiver or care recipient fostered the caregiver's self-esteem. Expressions of affection and empathy towards the caregiver or recipient were also described. Trust was demonstrated by actions that showed the caregiver that the network member had confidence in their caregiving abilities .

> *Because he does phone every two or three weeks and he's more concerned about me than he is his dad. (CONCERN)*
>
> *I could discuss my concerns about her [mother-in- law] and she would ...listen... (LISTENING)*
>
> *He [the family doctor] used to call me the "dragon lady"....[it] was an endearment term, because he said, you're like the Chinese, you care about.....the older people.." (ESTEEM)*
>
> *But the association with the other people from the trailer club has been a good feeling sometimes (AFFECT)*
>
> *I can't solve everything but it's nice they think I can. (TRUST)*

Informational Support

Informational support was commonly utilized and more often provided by formal sources of support, although informal sources also supplied this type of support. Informational support is comprised of information, advice,

suggestions or directives. Information was identified as being data or facts, usually supplied by health care professional and support groups. Advice was in the form of guidance or counselling, usually from knowledgeable sources, such as friends who had similar caregiving experiences or health care professionals. Suggestions were usually from informal network members, based on their own personal attitudes, experiences and beliefs.

> *I actually got some information out of the newsletter... information that I thought was useful about drugs and there's lectures. (INFORMATION)*
>
> *...but when it comes somebody has a problem they are all there to give you a tip or tell your "Do this or that" you know. (ADVICE)*
>
> *...he's very good for suggestions, he's very good to help out in terms of helping you sign papers and get things. (SUGGESTIONS)*

Appraisal Support

The least utilized type of support (or perhaps the least offered) was appraisal. This type of support was characterized by affirmation, feedback or social comparison, and was offered more often by the informal members of the social network.

> *...so does [the doctor] , saying when [my husband] was home he lasted a lot longer because of the care I gave him. (AFFIRMATION)*
>
> *.. he said to me " I know you always do the best for Mum." (FEEDBACK)*

..she's coped with Alzheimer's in her own grandfather, so she certainly knew and understood, it helped. (SOCIAL COMPARISON)

Social Networks and Support Available

Derived from the interview data, Table 3 (shown below) depicts the different types of support that the women caregivers perceived to be provided by the three types of social networks identified in the typology.

Table 3.

Types of Support Reported by Network Type

TYPE OF SUPPORT	TYPE OF SUPPORT NETWORK		
	Diverse	Semi-diverse	Kin-focused
INSTRUMENTAL			
Labour	a	a	c
Aid in Kind	b	c	c
Money	c	d	c
Modifying the environment	c	d	d
EMOTIONAL			
Concern	a	b	c
Trust	b	c	c
Listening	c	c	c
Affect	c	c	c
Esteem	c	c	c
INFORMATION			
Information	b	b	c
Advice	c	c	c
Suggestions	d	c	c
APPRAISAL			
Social comparison	c	d	c
Feedback	c	d	d
Affirmation	c	c	c

a- frequently reported
b- sometimes reported
c- infrequently reported
d- never reported

The women belonging to diverse and semi-diverse social networks proportionately described a similar number of examples of all types of support with the exception of appraisal support. Those caregivers with kin-focused social networks described proportionately fewer instances of instrumental and informational support. These caregivers also related a similar number (proportionately) of instances of emotional support and a higher number of instances (proportionately) of appraisal support than the women in the two other types of support networks. In all cases, appraisal support was perceived as being available much less frequently than other types of support.

Types of Support Perceived to be Insufficient

Table 4. (shown below) depicts the types of support that the caregivers perceived to be insufficient from their social networks. Because there were some discrepancies between the ASSIS data and the interview data, the table depicts interview data only. These discrepancies will be discussed later.

Table 4.

Types of Support Perceived as being Insufficient by Network Type According to Interview Data

	Diverse	Semi-diverse	Kin-focused
Instrumental	x	y	x
Appraisal	y	z	z
Emotional	y	z	y
Informational	y	y	z
General	y	x	y

x sometimes mentioned
y infrequently mentioned
z never mentioned

Insufficient Support from Diverse Social Networks

Information from the interview data revealed that for caregivers with diverse social networks, instrumental support was most lacking and that was mainly from formal sources, such as homecare and long term care. A few caregivers cited an occasional lack of instrumental support from informal sources. Informational support, particularly from formal sources such as health care professionals, was often considered to be insufficient. Some caregivers noted an emotional lack of support, mainly from relatives. In a few instances,

the caregivers described a general lack of support from their social networks, but did not identify any specific type of support or any specific source as being deficient. Affirmation was perceived to be generally unavailable from relatives for one caregiver. The ASSIS data indicated that a few of the caregivers felt a lack of all four types of social support.

Insufficient Support from Semi-Diverse Social Networks

According to interview data, many caregivers with semi-diverse social networks felt a general sense of support to be lacking, mainly from their relatives. In addition they perceived a lack of instrumental support, both from formal and informal sources. A few of the caregivers also described a lack of informational support from formal sources. The ASSIS data showed that a few of the caregivers perceived a lack of all four types of support.

Insufficient Support from Kin-focused Social Networks

Caregivers with kin-focused social networks perceived a general lack of support from relatives and a lack of instrumental support from both formal and informal sources. Social networks were perceived as being delinquent in providing emotional support by a few of the caregivers. However, the ASSIS data indicated that caregivers with kin-focused social networks suffered a lack of informational, appraisal and emotional support, but surprisingly, instrumental support was not reported to be lacking even though the interview data indicated

that instrumental support was lacking for these caregivers.

Perceived Satisfaction with Support

All but one of the caregivers with diverse social networks were satisfied with the support that they received and none noted any changes over time. Four of the seven caregivers with semi-diverse social networks were satisfied with their support and one noted a slight increase in the support over time, while another noted a decrease in the support over time. All four caregivers with kin-focused support networks were dissatisfied with the support that they received and one reported that there was a decrease in the support that she received over the duration of the study. The rest noted no changes.

Common Variations in the Caregiving Context

It is important to consider variations which may have influenced the women caregivers' social networks and social support. The relationship of the caregiver to the care recipient, the place of residence of the care recipient and other caregiving responsibilities of the caregivers were examined.

Caregivers of Spouses

Eight of the care recipients were the husband of the caregiver. Five of these care recipients lived with the caregiver, two care recipients lived in a long term care (LTC) facility and one moved from home to a LTC facility during the course of the study because of a deteriorating physical condition.

One of the care recipients who was a spouse died during the course of the study.

Of the five caregivers who had their spouses living with them, only two were satisfied with their social support. Both of these caregivers had enjoyed a close relationship with their husbands before assuming the caregiver role and this close relationship continued into the caregiving relationship. Both husbands experienced good physical health, and though they had quite considerable cognitive impairment, the caregivers were still able to live a pleasant and comfortable life with their spouses. There were changes in their relationships with their husbands, but both caregivers adjusted to these changes with a minimum of difficulty.

> *...I would say just him being here for now and being just a partner. Ah, it would be nice if you get maybe a little more praise, but you don't. And you know they appreciate it, but they just don't want to tell you...If I see him walking down the street, I'm glad I've got him for another day.*

> *We do so many things; [my husband] and I do so many things together. We always have and that is just a continuing pattern.., which works very well.*

The other three caregivers who had their spouses living with them were not satisfied with the support that they received. Two of these care recipients required a tremendous amount of physical care, which resulted in a lot of stress and physical labour for the caregivers and prevented them from pursuing of a

social life or their own interests. Both of these women had financial problems and also were constantly experiencing conflict with the health care agencies and health care providers from whom they received assistance. Both felt that the health care system did not fully address their needs as caregivers.

> *So I was between the hospital [which] would like to send him home and discharge him and homecare what had the red tape from here to Rome, it was just ridiculous.*
>
> *Every time I asked [homecare] for something, "Well we have to have a meeting. We have to discuss".*
>
> *Because we don't have any family, he came home...and I care for him.....there really wasn't too many questions about the appropriateness of where he was going....or whether or not I was able to do it, it was an assumption.*

The remaining woman in this group was for the most part rather ambivalent about the support that she received. She stated that she often did not receive as much support as she may have required, but also added that this may have been due to the fact that many people perceived her to be in control and capable and therefore not in need of any support. Her main dissatisfaction with the support that she received stemmed from the deteriorating relationship she had with her husband's relatives. This affected her greatly as she and her husband had been close to his family in the past.

> *I have a brother in the city who's married to my husband's sister. And I guess they're still in denial. His own family has not been able to accept it, for whatever reason...I guess maybe what it is... their favourite uncle*

became kind of a cranky person about certain things and was very outspoken...And ah, they have not accepted it and it hurts.

Two of the three caregivers whose husbands were in a long term care facility by the end of the study, were also not satisfied with the support that they received from their social networks. Both women felt that some of their friends and even family did not realize the stress of their caregiving roles and did not provide appropriate or adequate support. They also were often dissatisfied with the care that their spouses received in the LTC facility or with the assistance that they received from the government.

The way that I feel...we're shut off. (when nobody comes to visit her husband in the LTC facility).

The government just lets you go to food banks. (Rather than providing adequate pensions for the disabled and their spouses)

Caregivers of Other Relatives

The other women in the study were caregivers to a parent or a parent-in-law, and in one case, a grandparent. Eight of these eleven caregivers were satisfied with the support that they received. One of these satisfied caregivers was also responsible for a father-in-law who resided in a LTC facility. All but two of the care recipients were residents of a LTC facility when the study began and all the care recipients were in a LTC facility when the study ended, because of changing care needs. Three of the care recipients (who were not

spouses) died during the study's time frame. Some responses of this group of caregivers follow.

> *I have friends who are very supportive and work mates are very good support and I have a very strong community of people who support me, so I'm very fortunate.*
>
> *So there's a lot of support and I know that if I was stuck for something there would be a lot of people there.*
>
> *I think that I have a pretty good support system.*

Although a majority of these women who were caregivers of their mothers were satisfied with the support that they received from their social networks, many were not satisfied by the care that their mother received in the Long term care facility. Most felt that the staff did not monitor their mothers' condition adequately or give them good care. This resulted in increased stress as they not only had to contend with other issues surrounding their mothers' residing in the LTC facility, but they also felt responsible for supervising their mothers' health care.

> *And I had to bring it to the staff's attention that there was something definitely wrong with my mother....I suggested to the head nurse that they test her urine.*
>
> *But it kind of concerned me that anytime I made a big fuss..that they [the LTC staff] would be rough with her or something like that.*

Of the four caregivers who were not satisfied with their social support,

three were caring for a mother and one was caring for her grandfather. Two of these caregivers had young families of their own and the other two also cared for grandchildren on a regular basis.

A common theme of these caregivers was that each one expressed a lot of guilt, either with regards to the fact that the care recipient was living in or had to be moved to a LTC facility during the study or because they felt that they should be doing more for their relative.

> *I'm having a hard time letting him go because I don't want him to be in an institution ...and I don't think he needs to be there.*
>
> *...but there's still the guilt that, you know, you could be doing more. You should be doing this.*
>
> *And with the guilt feeling that I have...that...I'm letting Mum down at this time.*

The three women, who cared for their mothers and were not satisfied with the support that was given them, all stated that they received little or decreasing amounts of support from their families. The woman who cared for her grandfather received adequate support from her husband and children, but was very dissatisfied with the support that she received from other family members, such as her mother, grandmother and siblings,etc.

Chapter 5

Discussion

The purpose of this study was to examine the social networks of a group of women caregivers in terms of membership, the caregivers' perceptions of the presence and/or absence of various types of support and conflict, and their satisfaction with the support that they received. In order to get a complete picture of the social networks and support perceived by this group of women caregivers, they were interviewed over a period of 18 months.

Although many studies in the last ten years have been conducted on caregivers (eg., Brodaty & Hadzi-Pavlovic, 1990; Neary, 1993), their social networks (eg., Cohen, Teresi, & Blum, 1994; Fiore, Becker, & Coppel, 1983) and the support that they receive (eg., Clipp & George, 1990; Tausig, 1992), the focus has been predominantly on the effects of caregiving on caregivers and the association of social support with the caregivers' health and life satisfaction. However, little investigation has been conducted into the qualitative characteristics of the social networks of caregivers, the types of support that they perceive to be present or lacking from the various members of their networks and their satisfaction with the support that they received.

Network Analysis

Social networks of caregivers have traditionally been analyzed with mainly quantitative measurement (eg. Cohen, Teresi & Blum, 1994), looking at structure and function, although recently some researchers have used qualitative data collection methods such as interviews (Staight & Harvey, 1990). The disadvantage of a quantitative type of network analysis is that it tends to look at social networks at only one point in time and often does not consider all the dimensions of social networks and the support that they provide.

Wenger (1991) reported on a qualitative longitudinal study that was conducted on rural older persons in North Wales. She developed a typology of social networks from interview data that has some relevance to the typology from this study. She discovered five network support types. They were:

1) The family dependent; with a primary focus on kin ties, close family relationships and few peripheral friends and neighbours.

2) The locally integrated; includes close relationships with local family, friends and neighbours.

3) The local self-contained support network; with infrequent contact with nearby kin members. Reliance is upon neighbours, though persons with this type of network tend to adopt a household-focused lifestyle.

4) The wider community-focused; with a dynamic relationship with distant

relatives and significant association with friends in the area and a few neighbours.

5)The private restricted; with an absence of local kin other than a spouse (if present), and minimal contact with neighbours or the local community.

Wenger suggests on the basis of the literature and the qualitative data from her study, that it is possible to theorize about attributes of the types of social networks defined in her study. The locally integrated and wider community focused networks were better able to handle life events due to their size, links with other social networks and " low levels of isolation and high morale" (p. 152). The family dependent, local self-contained and private restricted networks tended to be less supportive, as they were smaller in size and had fewer resources.

Aspects of Wenger's typology of social networks are similar to some of the characteristics of the typology of social networks that was developed from this study: the diverse network, composed of a large number of many different types of members, the semi-diverse network, which has some variety in membership as well as the core family and friends, and the kin-focused, composed mainly of a small number of relatives and a few friends and formal members. Like Wenger's locally integrated and wider community focused networks, the diverse networks were better able to meet the needs of the

caregivers, who were able to rely upon a variety of members to provide support. However, relatives, both near and far, were an important component of the diverse network, unlike Wenger's community focused networks. Wenger's family dependent network and this study's semi-diverse network both were composed predominantly of friends, relatives and neighbours who were at times unable to provide the full amount of support that was needed. Both Wenger's private restricted and this study's kin-focused networks were composed of few members, mainly family and a few friends or neighbours, who were not often able to meet all of the support needs. Wenger, however, did not go on to identify what types of support and conflict were present and/or absent, and the overall perceived satisfaction with the support. As well, Wenger's study was focused on elderly people and this study was looking at caregivers of elderly persons; the caregivers were not necessarily elderly themselves.

Cohen et al (1994) examined 59 Alzheimer patient-spouse caregiver dyads in order to study the effects of social networks on alleviating caregivers' mental distress. Their correlational study used a variety of measurement instruments. Two of their findings are pertinent to this study.

One finding was that the dimensions of the caregiver network are associated with the severity of the patient's illness but not the duration of the

illness. This finding is well illustrated by the kin-focused social networks of the caregivers of confused older persons. Some of the care recipients in this study were quite physically debilitated and demanded a great deal of time and attention from their caregivers. This resulted in little or no time being available for those caregivers to investigate or enlarge their social networks in order to meet their expanding support needs. Consequently, they described insufficient support.

The length of time as caregiver ranged from one year to over 21 years . Some women had been caregiving for many years and belonged to diverse social networks, while some had been caregivers for less time and belonged to semi-diverse or kin-focused networks. The membership or extent of the social network did not seem to be related to the length of time that the women were caregivers.

Another finding of the Cohen et al (1994) study that was of interest to this study was that increased severity of the illness did not result in increased network size, but did result in members assuming new roles. Cohen et al's conclusion is also supported by the findings of this study. Women in this study who cared for the more severely handicapped recipients often had the smallest social networks, despite their expanding need for support. In fact, some of the networks actually decreased in size as the care recipient became

progressively more dependent, often because of a diminishing commitment on the part of some network members. As well, social network members who originally assumed only the role of child or friend or neighbour etc., often assumed additional roles, as the caregiver and care recipient were less able to perform certain tasks. This often occurred in the areas of home and automobile maintenance, and lawn care.

Israel et al (1984) found that caregivers benefit in different ways from certain types of networks. For example, networks that provided affective support, closeness and reciprocity did much to enhance psychological well-being, but other networks that supplied instrumental support and close geographical proximity were more helpful in crisis situations.

The above findings are in accord with Walker et al (1977), who postulated that social networks which are small in size, comprised of members who know each other (high density), are similar in characteristics (homogenous), live close by (low dispersion) and have close relationships with the caregiver, present a consistent and unchanging identity with high emotional support. However, networks with a large and varied membership, that may provide only weak ties and are geographically scattered may actually be of more benefit in crisis situations as they provide access to new social contacts, and may supply new and different information.

While the results of this study support the findings of Walker et al (1977) and Israel et al (1984) that a network with members living in close proximity can provide more instrumental support, emotional support was still provided by those members who lived a distance away. In this study, similar characteristics of network members did not seem to be related to the caregivers' satisfaction with their social network, whereas close relationships were perceived as critical. What emerged as being most important was that the network be comprised of a varied membership (of a medium to large size) which provided various types of support. This type of network satisfied most if not all of the caregiver's needs.

Types of Support Present or Absent

The types of support available from the social networks that are perceived by the caregiver to be insufficient are an important consideration. This study defines types of support as being instrumental, affective, emotional or informational (House, 1981). A few studies have examined these types of support separately to determine their individual importance to the caregiver. Some studies looked at the characteristics of the social networks and outlined the type of support that networks of varying characteristics provided.

After intensive analysis of the relevant literature, Israel (1982) stated that social networks with high density and homogeneity and low dispersion

were likely to provide high emotional support. An increase in network size would be predicted to result in the additional provision of instrumental support. Networks with low density and homogeneity would be most likely to provide varied and new information. Those networks with few linkages are the ones most likely to provide access to new social contacts.

The results of this study are not always consistent with Israel's (1982) conclusions. Both caregivers with diverse networks (with low density) and kin-focused networks (high density) described perceptions of emotional support. However, the caregivers with diverse and semi-diverse social networks did describe more examples of perceived instrumental support than did caregivers in the kin-focused networks which were smaller in size.

Other studies have examined the types of support provided by individual members of the social networks. In a descriptive study Spaid and Barusch (1992) looked at the association of social support with a sense of strain in spousal caregivers. They discovered that daughters provided the most emotionally close social contacts, followed by friends and neighbours and then sons. Daughters, others and friends provided the highest proportion of social support, while others provided the most significant amount of helpful contacts. However, the terms social contacts, social supports and helpful contacts are rather broad and not well-defined and therefore are hard to relate to the present

study.

Wenger and Shahtahmasebi (1991) stated that spouses (unless unable) provide total support, children provide instrumental and emotional support, siblings and friends provide mainly expressive support, neighbours provide limited instrumental help and the extended family provide primarily symbolic support. Similarly, the findings of this study support the view that family members tend to supply most of the instrumental and emotional support. Non-kin network members tend to supply small amounts of instrumental support (such as a neighbour mowing the caregiver's lawn) and more aid-in-kind types of support (such as visiting), and expressions of concern and sympathy.

Cohen et al (1994) reported that as the severity of illness (of the care recipient) increased, the informal network provided more material support along with the customary role of providing advice, intimacy and friendship. Formal networks, on the other hand, provided more affective support along with the usual material support. In this study however, affective support was rarely provided by formal members of the social network, although the other findings in this study are consistent with Cohen's results.

Conflict

There has been an increasing awareness of the necessity to address the phenomenon of conflict within social networks and the effect this may have on

caregivers (eg., Rook, 1984; Tilden & Gaylen, 1987). Whereas initially, social networks and social support were seen as synonymous and only beneficial, now researchers are aware of the need to differentiate between social networks and social support and the impact that conflict has on the well-being of caregivers. Rook (1984) proposes that "negative social interactions have more potent effects on well-being than positive social interactions" (p. 1106).

A descriptive study by Spaid and Barusch (1992) examined the association between sense of strain and social support. They reported that adverse social contacts (which result in conflict) are important predictors of the amount of strain experienced by caregivers. A sense of strain may have a considerable effect on caregiver satisfaction with the support that is received from the social networks. In this study, situations of conflict ranged from isolated incidents in normally positive relationships, to a constant state of conflict from network members who in many cases also provided support. At most times the conflict was centred around the caregiving experience. Sometimes network members did not provide satisfactory care or support to the caregiver and/or the care recipient, and were nonsupportive or in disagreement with the woman's caregiving endeavours. Those caregivers who were the least satisfied with the support that they received were also the ones who described frequent instances of conflict with network members.

The amount of conflict experienced by caregivers varied across the types of networks that were identified in the typology developed from the study data. Those caregivers with diverse networks reported only occasional and generally isolated incidences of conflict. These caregivers were also predominantly satisfied with the support that they received. Those caregivers with semi-diverse and kin-focused networks identified more frequent occurrences of conflict, that often were continuous in nature. Caregivers with these two types of social networks tended to be less satisfied with the support that they received.

It is not possible from this study to determine why those with diverse networks had less conflict and were more satisfied with the support that they received than the caregivers with the other two types of social networks. The findings from a study by Wilson, Moore, Rubin and Bartels (1990) may offer one explanation. In a correlational study of social support networks of 77 informal caregivers of the chronically ill, they discovered that it was the quality of social interaction with friends, rather than the social network structure, that was critical for caregiver support. Studies of conflict in social networks indicate that negative social interactions put more strain on the caregiver (eg., Rook, 1984) and have a direct impact on life satisfaction. This would be reflected in the satisfaction with the support that is received. In a correlational

study by Fiore et al (1983), 44 caregivers of spouses with Alzheimer's disease were asked about their social support and the effect of conflict and the absence of desired and expected support. An important finding was that conflict and unmet needs resulted in increased stress and depression for the caregivers.

As discussed earlier, interview data identified health care and other professionals in the women's social networks as sources of conflict more often than informal members. Conversely, the Ecomaps and ASSIS named informal members as sources of conflict far more often than health care and other professional network members were identified. This discrepancy likely arises because health care and other professionals were rarely identified on the ASSIS and only a little more often on the Ecomaps. These discrepancies are congruent with the findings of Morgan (1990). In a study of caregivers for family members with Alzheimer's disease, Morgan used questionnaires (quantitative measurement) and discussion groups (qualitative measurement) to obtain data. The networks derived from the questionnaires contained family members, a few friends and hardly any formal ties. However, formal ties were much more frequently mentioned in the descriptions of the social networks derived from the discussion groups. He stated that "the two data collection strategies give different pictures of the relationships in caregivers' social networks" (p.206)

The Caregiving Context

The relationship of the caregiver to the care recipient, place of residence of the care recipient and the other responsibilities of the caregiver are all factors which influence the impact of the social networks and perceived social support of caregivers. As Morgan (1991) notes, a spouse's high level of commitment to the caregiving role is often considered a natural progression in a relationship that has often developed over three or more decades. A child, on the other hand, often acquires the role as caregiver more abruptly and often has other responsibilities to fulfil.

Although the role of caregiver to a spouse is an expected one, this does not automatically mean that spousal caregivers belong to social networks that will provide the needed support. Of the eight women who were caregivers for their husbands, only three were satisfied with the support that they received. All were dissatisfied with the professional and government support that they received. This dissatisfaction was with the direct care given to the care recipient, or with the financial or other supportive services directed towards the caregiver. In their multidimensional study of caregivers of demented adults, George and Gwyther (1986) discovered that spousal caregivers exhibited lower levels of well-being in measures of physical health, mental health, financial resources and social participation, than did adult children or other relatives. The

time-consuming role of spousal caregiver resulted in less time spent pursuing interests or socializing; activities that would potentially expand the women's social networks and increase the possibility of emotional and other types of support.

Support satisfaction did not appear to be higher when the care recipient lived in a LTC facility, although there was less physical burden for the caregiver. Staight and Harvey (1990) conducted a correlational study of fifty women caregivers. Some were caring for their husbands at home while the others were considered "secondary" caregivers as their husbands were in a LTC facility. The findings indicated that both groups of women caregivers were equally susceptible to the "burdens inherent in caregiving" (p.101), and that the only difference was that the "secondary" caregivers complained less of time constraints. Colerick and George (1986) reported that caregivers were more likely to report decreased support from family and friends after their husbands were institutionalized. In the current study of women caregivers, there were some instances where there were a few networks members who were visiting the care recipient in the LTC facility with a decreasing frequency as time went on. This left the caregiver with complete responsibility for the well-being of the care recipient. Both spousal caregivers and nonspousal caregivers reported this problem.

In addition, for wives and other caregivers in this study, the placement of the care recipient in a LTC facility often engendered feelings of guilt. Willoughby and Keating (1991) reported the same response in a grounded theory study which examined the process of caregiving. Their research indicated that caregivers often express frustration and helplessness after institutionalization of the care recipient, indicating a continuing sense of responsibility. They suggest that the negative feelings towards the staff of the institution were in part a result of the caregivers' guilt in response to their perceived abdication of care responsibilities.

Other caregiving responsibilities of the women in this study also impacted on their satisfaction with the support that they received from their social networks and on how they were able to interact with their social networks. Of all the women who were not satisfied with the support that they received, most had other caregiving responsibilities. Some were responsible for their young children and others were caring either full-time or part-time for grandchildren.

Stone, Cafferta and Sangl (1987) reported in their national profile of caregivers of the frail elderly, that those with other responsibilities suffered negative effects on their well-being. The Canadian Aging Research Network (1993) surveyed employees from eight Canadian organizations and found that

26 percent of the respondents combined childcare responsibilities with the care of an elderly relative. Compared with respondents who had no caregiving responsibilities, those with dual responsibilities were at the greatest risk for problems of stress, work and family conflict and other personal costs.

Changes Over Time

An important aspect of caregiving is that it is usually conducted over a period of time. In this study some of the women were caregivers for just one year and others were caregivers for over twenty years. These women caregivers were all at different stages of their caregiving careers. There were changes in the social networks in terms of members either moving away or dying, or contributing more or less support. The cognitive or physical condition of the care recipient often declined and in some situations the care recipient died. Two caregivers assumed other caregiving responsibilities. Despite all these changes, most caregivers reported that there was little if any overall variation in the support that they received. This finding is consistent with studies such as one by Clipp and George (1990). In a one year study of 376 adults caring for a family member with Alzheimer's disease, they concluded that though there were some fluctuations in the social support received, in most cases support in the caregiving situation was stable.

Limitations of this Study

A limitation of this study is that the researcher was not able to confirm her findings with the respondents. This limitation was addressed to some extent as the researcher did have access to the original researchers, who are also experts in this field. Another limitation is that the respondents were all volunteers and therefore may not be truly representative of this population of caregivers. However, because the informants were recruited through advertisement, it was possible to include caregivers who may have limited contact with the health care system.

Implications of the Study

This study has implications for future research on the social networks of women caregivers. There are also implications for the practice of health care professionals who interact with these caregivers.

Implications for Future Research

As noted in the literature review for this study, there has been no measurement instrument developed that profiles social networks looking at all the relevant dimensions. There is a need to develop or refine measurement instruments which assess multiple qualitative characteristics of social networks as well as the presence of conflict and perceived satisfaction with support. Information about network size alone provides little direction for practice.

Further research is needed to identify the factors that predispose to conflict and the consequences for the caregiver (such as depression and stress) which may arise from long term exposure to conflicted relationships for the caregiver. Research is also needed which considers variations in the importance of different types of support for caregivers. For example, in this study, perceptions of appraisal support were rarely described as being received by the caregiver. Is this because it is not required by the caregiver or is it just not provided by the social network? The effects on caregivers of too little appraisal support is certainly an area that needs to be further researched.

Implications for Nursing Practice

Nurses and other health care professionals can assist caregivers to identify all the resources that are available to them. Information about these resources needs to be available at the most common points of entry to the health care system. Examples of the information caregivers require include knowledge about sources of support that are available to them, how to apply for appropriate funding through various government agencies, how to get their relative assessed for potential future long term care placement, what support groups are available that are appropriate to their situation and other legal and financial considerations.

Informal members of the caregivers' social networks, especially

relatives, friends and neighbours are the major sources of support. Public education on how to support the caregiver most effectually could enhance their effectiveness. Community, church and service groups also need to be encouraged to develop programs that will assist those caregivers who may have inadequate support from their existing social networks.

Nurses and other health care professionals need to be aware of the impact that conflict can have on the caregiver. By using the six categories of conflict discussed in this study, health care professionals can identify the types and sources of the conflict that may be present in a caregiver's social network. Based on this identification, health care professionals can help the caregiver to develop strategies to resolve the conflict, to look for alternate sources of support or to learn how prevent the emergence of conflict.

In addition, health care professionals themselves are often the source of conflict for the caregivers. Professionals need to look at their own programs and interactions with the caregivers and ascertain what types of support the caregivers require from them and how to minimize the incidence of conflict. Homecare professionals need to be able to make immediate decisions about the allotment of resources. If they are unable to provide a specific type of support, they should then be able to provide the caregiver with information on where to locate that specific resource. Long term care staff need to include caregivers in

the development of the care plan for the care recipient. They also need to be attuned to the changes in health status of the care recipient and acknowledge the caregiver's expertise in this area.

Nurses and other health care professionals can also assist caregivers by recognizing that the caregivers have different access to support. An assessment of caregivers' social networks and perceived support is important. Ongoing assessment will ensure that the caregivers' social networks are supplying the types of support required.

The typology of networks that was developed from this study needs further research in order to confirm that it is applicable to other caregivers of confused older persons. However, this network typology could be used in the assessment of caregivers' social networks to predict potential occurrences of conflict and/or dissatisfaction with the support received and to implement measures to prevent conflict and dissatisfaction from occurring. Health care professionals could use the typology to effectively distribute scarce financial and personnel resources. By using the three classifications of network type, the health care professional coould plan needed or potential interventions, depending on the support needs of the individual caregiver.

For example, caregivers who belong to a diverse social network, would probably be receiving an satisfactory amount of support and need only periodic

monitoring. Those caregivers with semi-diverse social networks ,that are presently providing enough support, may not need any intervention but would require more frequent monitoring. Those caregivers with kin-focused social networks and with semi-diverse social networks that do not provide the needed support, would require immediate intervention to ensure that their support needs are being met.

Conclusion

The findings of this study have major implications for those who are involved with the caregivers of the cognitively impaired. The typology of social networks that was derived from the data indicate that are variations in the composition of caregivers' networks. In this study, attributes of a network, such as size, diversity, and membership, were associated with differences in the caregivers' perceptions of and satisfaction with support. Conflict in relationships was also described, particulary the caregivers in the kin-focused network.

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Appendix A

Interview Guides from the Original Study

Initial Interview

Introduction.
1. Please tell me the story of how you came to care for.....
Probes: What are some of the examples of specific situations in which you experienced help (support) when you first started caring for .....? Please describe who was involved and what they do to assist you.
Caregiving Relationship.
1. What is a typical day like for you caring for .....?
2. In describing your relationship with (dependent adult), what do you contribute to the relationship? What does ..... contribute?

Support within the social network.
We are interested in the support you receive in general not only the support you receive in giving care to .....

1. During the past few weeks what are some examples of specific situations in which you experienced help (support)? Please describe who was involved and what they did to assist you.
2. From which relationship(s) do you receive most of your support or health? How would you describe these relationships (e.g., length of involvement,type of support, frequency of contact, difficulties)?
3. During the past few week while you have been caring for (dependent adult), what are some examples of specific situations in which you have given help to other people besides (dependent adult)?
4. How would you describe those relationships within which you provide most of the help in terms of length of involvement, type of support, frequency of contact, difficulties (other than relationship with dependent)?
5. Are you sometimes hesitant to accept or ask for help? If yes, please describe the situation.
6. Are you sometimes hesitant to offer help? If yes, please describe the situation.

Some of the women in the interviews have discussed non-support. Have you experienced non-support? Please describe who was involved and why you found them non-supportive.
Summary: Is there anything else in regard to support that we have not talked about that you would like to share with me?

Follow-up Interviews

Changes in Social Network
A. Help provided to others.
1. Have there been any changes in how you are able to help others since you first started caring for .....?
Could you please describe the changes?
2. Which if any of these changes have occurred since our last interview?
3. Do you expect any changes in the future? In what ways?

B. Help received from others.
1. Have there been any changes in how others have helped you since you first started caring for.....? could you Please describe the changes?
2.Which if any changes have occurred since our last interview?
3. Do you expect any changes in the future? In what ways?

Changes in Caregiving Relationship.
1. Have there been any changes in your relationship with..... since you first started caring for him/her? Could you please describe the changes?
2. Which of these changes if any occurred since our last interview?
3. So you expect any changes in the future? In what ways?

Final Interview Guide

This is the last time I will be talking to you. I would like to review with you some of the things you have discussed with me previously.

INSERT INDIVIDUALIZED QUESTIONS

Changes in relationships.
1. Are there any changes that have taken place in your relationships since our previous interviews? Please describe any changes in your relationships with others. Please describe any changes in your relationship with.....

Social network.
In our previous conversations I have asked you to select and describe situations in which you received or provided help. Today I will ask you for similar information using specific examples of situations other researchers have used. These questions may give us the same information as before or provided additional information. (The Barrera ASSIS will be used.)
Debriefing
As we conclude our discussions about your relationships with your friends and family while you are looking after ..... I would be interested in hearing your thoughts about the experience of participating in this study. In what ways, if any, has you involvement in the study influenced your thinking about your relationships and the process of give and take in your relationships.

Appendix B

ARIZONA SOCIAL SUPPORT INVENTORY SCHEDULE

In the next few minutes I would like to get an idea of the people who are important to you in a number of different ways. I will be reading descriptions of ways that people are often important to us. After I read each description I will ask you to give me the first names, initials or nicknames of the people who fit the description. These people might be friends, family members, teachers, doctors, or other people you might know.

If you have any questions about the descriptions after I read each one, please ask me to try and make it clearer.

A. PRIVATE FEELINGS

1. If you wanted to talk to someone about things that are very personal and private, who would you talk to? Give me the first names, initials, or nicknames of the people that you would talk to about things that are very personal and private.
PROBE: Is there anyone else that you can think of?

2. During the last month, which of these people did you actually talk to about things that were personal and private?
PROBE: Ask specifically about people who were listed in response to #1 but not listed in response to #2.

3. During the last month, would you have like:
1 = a lot more opportunities to talk to people about your personal and private feelings
2 = a few more opportunities
3 = or was this about right?

B. MATERIAL AID

1. Who are the people that you know that would lend or give you $25 or more if you needed it, or would lend or give your something (a physical object) that was valuable? You can name some of the same people that you named before if they fit this description, too, or you can name some other people.
PROBE: Is there anyone else that you can think of?

2. During the past month, which of these people actually loaned or gave your some money over $25 or gave or loaned you some valuable object that you needed?
PROBE: Ask about people named in response to #1 that were not named in response to #2.

3. During the past month, would you have liked people to have loaned or to have given you:
1 = a lot more
2 = a little more
3 = or was it about right?

C. ADVICE

1. Who would you go to if a situation came up when you needed advice? Remember, you can name some of the same people that you mentioned before or you can name some new people.
PROBE: Anyone else?

2. During the last month, which of these people actually gave you some important advice?

PROBE: Inquire about people who were listed for #1 but not for #2.

3. During the past month, would you have liked:
   1 = a lot more advice
   2 = a little more advice
   3 = or was it about right?

D. POSITIVE FEEDBACK

1. Who are the people that you could expect to let you know when they like your ideas or the things that you do? These might be people you mentioned before or new people.
PROBE: Anyone else?

2. During the past month, which of these people actually let you know that they liked your ideas or liked the things that you do? These might be people you mentioned before of new people.

3. During the past month, would you have liked people to let you know that they liked your ideas or things that you did:
   1 = a lot more often
   2 = a little more often
   3 = or was it about right?

E. PHYSICAL ASSISTANCE

1. Who are the people that you could call on to give up some of their time and energy to help you take care of something that you needed to do - things like driving you some place you needed to go, helping you do some work around the house, going to the store for you, or things like that? Remember, you might have listed some of these people before or they could be new manes.
PROBE: Anyone else you can think of?

2. During the past month, which of these people actually pitched in to help you do things that you needed help with?
PROBE: Ask about people who were named in response to #1 but who were not named in response #2.

3. During this past month, would you have liked:
   1 = a lot more help with things that you needed to do
   2 = a little more help
   3 = or was this about right?

F. SOCIAL PARTICIPATION

1. Who are the people that you get together with to have fun or to relax? These could be new names or ones that you have listed before.
PROBE: Anyone else?

2. During the past month, which of these people did you actually get together with to have fun or to relax?
PROBE: Ask about people who were named in #1 but nor in #2.

3. During the past month, would you have liked:
   1 = a lot more opportunities to get together with people for fun and relaxation
   2 = a few more
   3 = or was it about right?

G. NEGATIVE INTERACTIONS

1. Who are the people that you can expect to have some unpleasant disagreements with or people that you can expect to make you angry and upset? These could be new names or names you have listed before.
PROBE: Anyone else?

2. During the past month, which of these people have you actually had some unpleasant disagreements with or have actually made you angry and upset?
PROBE: Ask about people listed for #1 but not for #2.

H. PERSONAL CHARACTERISTICS OF NETWORK MEMBERS

Now I would like to get some information about the people you have just listed. For each person on the list, could you tell me:

1. What is this person's relationship to you? For family members, specify the exact relationship (mother, father, brother, sister, grandmother, etc.). For professional people, also specify the exact profession (teacher, minister, doctor, counsellor, etc.).

2. How old is this person?
3. What is this person's sex?
4. How long have you known this person?

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Appendix C

RESEARCH STUDY: WOMEN AS CAREGIVERS: PERCEPTIONS OF RECIPROCITY IN SOCIAL SUPPORT

DEMOGRAPHIC DATA

In order to describe the women who have participated in the study, we would like you to answer the following questions:

1. What was your age on your last birthday? (Years) _____

2. Indicate by an X the amount of formal education that you have.

Less than Grade 12	_____
Grade 12	_____
Some university or post-high school diploma	_____
University degree	_____
Graduate degree	_____

3. Into which category would you place your family income.

Less than $20,000	_____
$20,000 to $40,000	_____
Over $40,000	_____

4. a) Please mark with an X each of the major difficulties which the person you care for experiences.

unaware of the time	_____
unaware of where they are	_____
unaware of who is around them	_____
forgets events in the recent past	_____
forgets events in their early life	_____

b) Do you live with the older person you are caring for?_____

c) What is your relationship to the older person you are caring for? _____

Appendix D

Sample of an Ecomap